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Agency: HEALTH AND HUMAN SERVICES COMMISSION HHSC

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Your Comments About the Staff Report, Including Recommendations Supported or Opposed:

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TESTIMONY BEFORE THE SUNSET COMMISSION IN REGARD TO THEIR REPORT ON THE HEALTH AND HUMAN SERVICE COMMISSION OF THE STATE OF TEXAS

This testimony is in support of the report issued on October 7, 2014 in regard to the review of the Health and Human Services Commission of the State of Texas. The report is exact and on target. The 15 areas reviewed in the report are exact and need to be taken by the State Legislature as changes to be made. However, in my business we are always concerned about treating the “symptoms of the problem” and not the underlying “problems.” In my professional opinion, I believe that there are more serious problems than the 15 recommendations that serve as a symptom of these problems.

The first problem that I believe the State Legislature needs to examine is what is often called “goals/means displacement.” Goals of an organization may be displaced by the means that have been acquired to reach those goals.

Thus the “means” displace the “goals” by becoming more important than attaining the goals. There were no remarks in the Sunset Commission excellent report on how well the 5 agencies within HHSC are attaining their stated goals. I don’t think this is an oversight. To me, the report pulls into focus a very critical issue. This is the focus on funds (the means) being more important than the achievements of stated goals. Simply stated, the HHSC and its agencies focus more on protecting the budget than on the benefits achieved by having such an enormous budget.

How would I suggest this be handled? First of all I would encourage the Legislature to maintain more control over the budget of HHSC. In particular, I would suggest that there be a “fee for service” approach from the budgeting arm of the Legislature to HHSC over the 2 year period of the budget. If the HHSC agencies cannot set goals and meet those goals, they do not get the allocated funds. This shifts to a performance based approach to funding. Intervals of 3 months, 6 months or annually may be chosen for reimbursement of goals attained. They do not have to all be on the same schedule but it is important that something be done to show accountability of expenditures.

A second suggestion I would make in regard to the budget goals compared to the means of attaining those goals would be what is often called “OPM” or in this case it might even be “OPR.” I would ask the State Legislature to require that for each dollar allocated to an HHSC agency, I would require that dollar to leverage other dollars to be used to reach the stated goal.

OPM is of course Other People’s Money and OPR is Other People’s Resources. In management terms this is using “forced cooperation” among state agencies to work together. In my professional opinion, the reason for the “goals/means displacement” is that state agencies have budgets that work in parallel instead of in tandem. Because these budgets are parallel there are two things that happen that do not lead to better use of state funds. One is that there is an implied competition among state agencies for state funds. The second is that each state agency feels compelled to ask for an increase in funding each new funding cycle. This leads to a major effort on the part of each state agency to “protect the budget.” In fact, in my opinion, state agencies have protecting the budget as the prime effort (displacing the goals with means of keeping the budget in tact). This leads to an unwritten rule: Don’t do anything to embarrass the agency in front of the Legislature that may jeopardize the budget. And don’t allow funds to go un-used. Never turn back money to the state at the end of a fiscal period.

I have been told by more than one source that when the Legislature is in session, state employees are told “not to leave their desk because someone from the Legislature might call...” Do you see how important the budget cycle and budget increases are to state agencies? The state uses goal attainments as a way to leverage federal dollars. But state agencies do not see the necessity of realizing that having goals as a priority makes a difference in leveraging federal funds. This is why, in my professional opinion, that the state has problems with the Centers for Medicare Services, the Department of Justice, the Office of Civil Rights, and most importantly with the public.

I am not sure of the legal base for “forced cooperation” among state agencies, but if there is a need to change laws to allow state agencies to work together on mutual goals and this requires comingling money, then it needs to be done. An example of this would be the interface between DARS and DADS with the Texas Education Agency. Too often, the reason given for not doing something is “that is TEA money.” Such an approach is inefficient.

All dollars are green and the state needs to take the approach that funding is greater when there is leverage of services due to sharing costs. Even more to the point, about which I know more, is the concept of “transition.” This effort is horrible in Texas. Children with disabilities grow up to be adults with disabilities. But Texas Workforce, DARS, and other “adult services providers” keep a hands-off position on becoming aware of children with disabilities becoming adults and needed adult services. Too often, in my experience, the young adult is required “to start all over.” This means all new “disability determination,” “testing,” and often delays that serve to discourage young adults with disabilities from finding supports, modifications, accommodations, or useful occupation of their time once they reach 22 years of age. Look at all the money spent on I.D.E.A. programs in Texas and find out what the outcomes are for those students. How many of them have a quality of life that is to their potential abilities? How many of them are prepared for life in the community upon reaching 22 years of age? How many of those young adults benefit from all the funds that have been spent over the years. Do these effort lead to optimal community living? The links of the sausage of disability services are not connected in Texas and the results are poor standards of care, waste of tax payer money, and most of all a very lacking service delivery system.

Because of goals/means displacements, DADS has created a cottage industry of mini-institutions that are replacing the larger state institutions now called State Living Centers.

These “group homes” are not providing quality care. Their goal, again, is to be funded and to have funds increase.

These are for-profit businesses and their source for success is in doing a volume business. Thus the private providers must expand and expand to meet the profit margins for their businesses. Last summer a training workshop

was offered in Houston for private providers of group homes. The topic was transitions. The content included several speakers who talked about needed services for young adults, geriatrics, and long range supports necessary for persons who are disabled. I

was asked to speak at the conference. The turn out was very low. When the conference was over I asked the private providers I know why they did not come to the conference. To paraphrase their answer, "we do not do transitions..." Persons with disabilities have become a profit point for private providers. They do not plan on the individual learning new skills, developing independent living skills, nor being involved in the community.

Allow me to digress somewhat to underscore this point. I want to talk about an instrument that is used called the ICAP, or Inventory for Client and Agency Planning. Now Bruiniks and Woodcock are quality test constructors but the ICAP has it flaws when it is used by people who do not appreciate the ICAP's limits. The ICAP predicts the "level of need" of a person so that funds may be allocated to support and amend those needs. The ICAP is used in Texas by those private providers to establish the funding for an individual with disability. The level of need, therefore, cannot go down in Texas. That is, the client cannot need fewer supports. That would cost the private providers and would reduce their profit for their business. I could go on, but you get the picture. Needs cannot change in Texas. There is no incentive for a person to get better. The person with a disability has become a cost point for a for-profit business.

This leads me to mention OPR. HHSC is a closed system. They do not view the most powerful resource in Texas as a resource to their programs. These are the parents and families of persons with disabilities. Parents are the only true case manager a person will have in Texas. HHSC is supposed to provide these services, but the parents still have to manage services across the lifespan. Agencies provide services to age groups and when a person "ages out" of a service they are dropped. There is no connect. Look at the transitions that a person with a disability goes through and how the family must "reinvent their universe every September." Then comes the aging out of school and I.D.E.A. at age 22 years. The wheels fall off. Services must be provided only if the person "qualifies." This cases the individual onto the welfare system of food banks, food stamps, and other programs for those in poverty. Parents know more about their family member than any professional will ever know, but parents, in Texas, are not viewed as a resource. Why can't we use parents? The best program MH/MR had in Texas for the state schools was the "foster grandparent" program that involved retired adults being paired with a resident of a state school. It worked out brilliantly but was discontinued when de-institutionalization came on the scene and the agency did not want anyone coming on campus who might know that their residents could live in the community and be a part of a family. What if we had parents of persons with disabilities serve as mentors to new parents?

What if we had communities of parents who would share, support, and accommodate those individuals who are on "Interest Lists" and that amounts to about 100,000 persons in Texas waiting for services from HHSC.

What if we had B-4 Families? You know like in the Bingo game, B-4, but these are parents and families who have been there before. Families of persons with disabilities do not have "cultural grandparents" who may transmit the culture. Each family has to start at square one and invent their universe.

And this continues throughout the life of the person who is disabled. Why does HHSC not recognize the importance of parents helping parents? It would reduce costs in a major way. In fact, it might just be that by using "forced cooperation" among funded sources (OPR), HHSC could change the way persons with disabilities function in Texas. For example, for the past 30 years, Partner's Resource Network in Beaumont has been funded to train parents of persons with disabilities to become case managers of their family member who is disabled. How much time, effort, and energy is being used by HHSC to utilize this existing and well funded program? Do the people in HHSC know why PRN is funded by the federal government? There is a program in Lubbock called the PEN project. It trains parents in "leadership training" to help other parents. Does HHSC work with this program? HHSC does support Parent to Parent but that program has been downsized to the point of almost not existence. Why are parents not trained to be partners with HHSC?

I made a bad impression at a stakeholders meeting for DADS held in Austin when I asked the staff of DADS what they were doing for those individuals on the "interest list." Now the words interest lists is so humorous that it is difficult to talk about it without laughing. It used to be called a "waiting list" and it was a waiting list of those waiting for services from HHSC's agencies. I work in medical settings. We cannot have a "waiting list" or an "interest list" in medical services. Yes, you may get "take 2 aspirins and call me in the morning," but once a person contacts a person in the medical field, that person is a patient. This means that a person walking into an emergency room, a clinic waiting room, a healthcare provider's office, or into a hospital, they are a patient and there are ethical and medical reason that person is helped immediately. It may be triage to use other resources, but that person is a patient and especially that person is YOUR patient. You cannot deny them services. Such is not the case in HHSC. I

feel that if a person has a disability and applies for services, that person becomes a customer. Yes, customer. HHSC does not have customers, that is persons who receive benefits from HHSC and who are a partner in the process. Only yesterday, November 11, 2014, the head of the Veterans Administration issued a new initiative for the VA. He called for more "customer centered" services. He wants veterans to have a more active role in guiding how the VA acts, treats, and supports veterans. As a veteran of the Korean Era, I watch for such changes. This means that it is now called MyVet instead of the VA. We have our own web site where we can go at any time and see our schedules, read out own records, see our own lab tests and diagnoses, talk about our needs, and receive support. It was made very clear that the VA System exists for veterans and was there to be a partner with veterans instead of an "agency." What would happen if HHSC used this model? What would happen if parents of persons with disabilities found out that there was an ongoing support for them in their efforts to raise, protect, and support their family member with a chronic set of problems?

I really want HHSC to be successful but I want it to be current and in the 21st Century. I am tired of having Texas rated at the lowest level in disability services (www.disabilitycoop.com/2013/05/02/stats-ranked-disability/17855/).

Especially when I see 24 Billion Dollars being spend in the state for Health and Human Servi

Any Alternative or New Recommendations on This Agency: Restructure the HHSC to a customer satisfaction approach to include parents of persons with disabilities as a resource instead of a "consumer" and making better use of existing programs and resources in Texas to improve consistent ratings of Texas in the bottom of the list of disability service providers

My Comment Will Be Made Public: I agree

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Updated Testimony: November 13, 2014

Focus on Persons with IDD and other disabling conditions

Neurogenesis

Neuroplasticity

ABA

Persons with disabilities “Have a Longer Growing Season”

Perhaps their best learning happens in their 20s and 30s
Murdina Desmond, M.D.

The goals of services to all persons including persons with disabilities
must be

- 1. To prepare them to live in the community**
- 2. To prepare them to occupy their time in a productive manner**

Difference between habilitation and re-habilitation

Lifespan learning is available to all citizens except those with disabilities.